Effect of job coaches on employment likelihood for individuals with mental retardation

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Objective: Determine whether the number of job coaches provided by local nonprofit disability service providers ("boards") significantly affected the employment outcome for individuals with mental retardation (MR) in South Carolina in 1997.

Study Design: Health, demographic and IQ information for individuals with MR (IQ 20–74) were matched with employment information derived from written surveys supplied by the boards. The study group comprised 431 employed and 6659 unemployed individuals. Logistic regression was used to assess the relationship between employment outcome and the number of job coaches per individual served.

Results: Job coach numbers per board varied from 0.00 to 2.48 job coaches per 100 individuals, with mean and median values of 0.97 and 0.87 coaches per 100 individuals. The effect of coaches on employment likelihood was approximately two times greater for individuals with low (IQ 20–39) than for high IQ (IQ 40–74), approximately three times greater for individuals in counties with low (3–6%) or intermediate (6–9%) unemployment and approximately ten times greater for individuals located in highly (>75%) urbanized counties. The likelihood of employment given the addition of one job coach per 100 individuals increased by factors of 0.37 to 2.49 in rural or moderately urban areas and by 3.79 to 25.70 in highly urban areas.

Conclusions: These results suggest that expenditures on job coaches are effective, and that such expenditures may be most effective if applied in urban counties with low or intermediate unemployment rates.

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1. Introduction

Employment is one of the top three stated goals for adults with disabilities [2]. Consequently, supported employment has emerged as one of the most popular disabilities initiatives in recent years. While access to supported employment slowed in the 1990s, this deceleration followed a rapid expansion of supported employment opportunities for individuals in sheltered workshops and activity programs in the late 1980s [1, 12,13,17,18]. Wehman and Kregel [18] demonstrated that a large group of individuals with severe mental retardation were able to obtain and sustain employment through local community agencies. Despite the successes, Albin et al. [1] estimate that only 10–12% of individuals who would benefit from supported employment now have access to this service. In addition, there has been concern that, as supported employment grew, emphasis would be placed on individuals with physical disabilities, brain injury and milder developmental delays [19,21]. In particular (and despite the widespread use of job coaching), progress in improving the likelihood of employment of individuals with MR has been slow [6,10,11,15].

The present study is part of an ongoing evaluation of employment of individuals with mental retardation (MR) in South Carolina. This evaluation is a collaborative effort between a State agency [South Carolina Department of Disabilities and Special Needs, hereafter DDSN] and the University of South Carolina School of Medicine. Both institutions wanted to iden-

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tify programmatic factors that could be changed to better use scarce monetary and labor resources. Schalock et al. [16] noted the limited capacity for data sharing by state MR/developmental disability (MR/DD) agencies. This study describes the use of service data by a state MR/DD agency to evaluate resource use and outcomes.

Immutable factors such as IQ, gender, race and age clearly influence employment [3,4,9,12]. However, we were uncertain and particularly interested in whether mutable factors, such as state-funded positions and financial support, would also significantly affect employment.

DDSN is responsible for providing services for individuals with MR in South Carolina. However, this charge is largely effected through the activity of 39 DDSN-supported local nonprofit service providers (hereafter "boards"). The relatively autonomous Boards typically operate within one county (34 boards), but five operate over two (four boards) or five counties (one board). The Boards provide residential, day program, job training, service coordination, and other support services to individuals with MR and to their families.

We examined the effect of one mutable employment factor – number of job coaches – on the employment of individuals with MR in South Carolina in 1997. We selected the use of job coaches because coaches represent the largest expense category in DDSN's employment services budget. We hypothesized that the incidence of employment in South Carolina would increase with number of job coaches per individuals with MR.

2. Methods

2.1. Data

The data for these analyses were largely provided by DDSN and by the local boards. For example, DDSN provided characteristics for individuals served by DDSN in 1996 and in 1997 from the DDSN Service Tracking System. Individual characteristics included individual identifier, age, gender, ethnicity, IQ score, physical impairments and/or medical involvement, and residential placement. DDSN also provided the number of job coaches employed by each board during July 1996 to June 1997 (due to budget considerations, this number was expected to remain constant during each fiscal year).

Average percent unemployment by county (1996) and percent households in urban areas by county (1990) were provided by the South Carolina Budget and Control Board's Office of Research and Statistics. Percent urbanization data for years subsequent to 1990 were not available.

The employment status of individuals with MR was determined by means of written surveys supplied to all boards in May 1997 and in May 1998 (applying to employment in calendar years 1996 and 1997, respectively). Each survey requested individual identifier, type of employment (see below), and the actual or estimated weekly earnings for each employed individual. Board supervisory staff for employment services filled out the surveys in both years. Using individual identifiers, the DDSN individual characteristics were then matched against the employment information provided by the board employment surveys. No individuals served by DDSN were contacted, interviewed or observed in this research.

Major types of employment included competitive, enclave (or mobile work crew), and workshop positions. Competitive (or community) work is performed on an individual basis with or without board assistance; enclave or mobile work is performed by groups of individuals for single or multiple employers, and typically via contract between the employer/s and the local board; workshop jobs are performed at board-provided facilities and utilize board-approved work or employment skill teaching. For the purposes of this analysis, competitive and enclave work were considered "employment"; workshop positions were not considered employment because such positions were generally publicly subsidized.

Inclusion criteria for this study included: 1) served by DDSN in both 1996 and 1997, 2) known county of residence in 1997, 3) unemployed in 1996, 4) age 19–64 in 1997, 5) measured IQ of 20–74, and 6) not autistic. While this study applied to individuals in 1997, individuals were required to be present on DDSN's files in 1996 so we could exclude previously-employed individuals. We required known county of residence in 1997 because county was used to match unemployed individuals with their respective boards. Age limits were restricted to the working population (ages 18–64) in both 1996 and 1997. As 18-year olds in 1997 would likely be in public school programs in 1996, individuals aged 18 in 1997 were excluded from the analysis. Autistic individuals were excluded from these analyses because we expected autism to significantly affect employment. However, their rarity (174 individuals) precluded testing this assumption. Persons with missing IQ were excluded because IQ was expected to have

a significant effect on the employment-job coach relationship. Persons with IQ less than 20 were excluded because they comprised a large proportion of the potential study population (24.1%) but were unlikely to be employed (8 of 2254 persons with measured IQ less than 20 were employed).

Given satisfaction of the inclusion criteria, employment was defined as earning $50 per week in a competitive job or enclave for at least six months in 1997. The minimum of $50 per week allowed the inclusion of individuals who continued to receive Supplemental Security Income (SSI).

To ensure data were reliable, a number of validity checks were carried out. First, we carried out rigorous data management and data cleaning procedures. Following discussion with data management at DDSN or with the Boards, suspect data was corrected or removed from the analysis. Secondly, we compared the employment rates for each local service provider for 1996 and 1997. All changes above ten percent (absolute) were confirmed or corrected through contact with the local employment supervisor. Finally, we distributed summary employment rate data to DDSN and to the local providers for their internal review.

2.2. *Statistical analyses*

Logistic regression was used to model the risk of employment as a function of the number of job coaches ("coaches") per board. Odds ratios, which closely approximate relative risks at low prevalences, were used to approximate the risk of employment. Coaches were standardized on a per-board basis by dividing by the number of individuals meeting the following criteria: served by DDSN in 1997, known county of residence in 1997, aged 18–64, and measured IQ 20–74. Using a denominator that exceeds the study group size acknowledges that job coaches assist individuals who do not meet our study criteria. In this case, the denominator exceeds the study group size by 1311 previously employed, 195 18-year old and 176 autistic individuals (the number of autistic individuals differs from that given previously due to a different variable removal sequence). The standardized value was multiplied by 100 to aid interpretation.

The effect of coaches on employment was assessed after adjusting for effect modifiers and confounders. Effect modification was assessed by means of a logistic model that contained coaches, all covariables and all potential covariable-job coach interactions. We considered the following potential effect modifiers: age [19–30, 31–50 and 51–64]; ethnicity [nonwhite and white]; sex; IQ [20–39, 40–49, 50–74]; health status [no loss of vision or hearing, and partial or total loss of vision or hearing]; seizure status [not diagnosed, and controlled or uncontrolled]; residence [supervised and unsupervised]; percent urbanization of county [0–25, 25–50, 50–75 and 75–100%]; and county unemployment rate [3–6, 6–9 and 9–19%]. Minority groups were merged because minorities other than African-Americans were rare (i.e., 2 employed and 81 unemployed). Effect modifiers with significant interaction terms (likelihood ratio test, $p \leqslant 0.05$) were retained in the model.

Confounding variables were defined as variables that were significantly related to both employment and to coaches. The relationship between a potential confounder and employment was judged significant if the log likelihoods of the full model (i.e., with the potential confounder) and the reduced model (i.e., without the potential confounder) were significantly different (Chi-square test, $p \leqslant 0.05$, significant effect modifiers included in both models). Significant relationships between coaches and potential confounders were determined by analysis of variance (ANOVA, $p \leqslant 0.05$). Potential confounders that were significantly associated with both employment and coaches were added to the reduced model sequentially. The confounder with the largest effect on the log likelihood was added first; subsequent potential confounders were added to the model only if they produced significant log likelihood differences given the presence of previously-added confounders. All analyses were performed in SAS [14].

3. Results

DDSN served 11990 individuals who were aged 19–64 in 1997. Exclusions on IQ included 186 individuals with IQ >74, 2254 individuals with IQ 0–20 (8 employed) and 1039 individuals with IQ missing (12 employed). File and employment exclusions included 284 individuals (7 employed) who were added to DDSN's files in 1997, 2 unemployed individuals with unknown county, and 961 individuals (688 employed in 1997) who were employed in 1996. Autistic individuals (8 employed and 168 unemployed) were then excluded. Following the above exclusions, the study group comprised 431 employed and 6659 unemployed individuals.

The distributions of demographic and health categories were similar for the restricted and full data sets

Table 1
Selected characteristics of study group

Characteristic	Unemployed in 1996[a]				Full 1997 file ($n = 9552$)[b]	
	Employed in 1997 ($n = 431$)		Unemployed in 1997 ($n = 6659$)			
	n	%	n	%	n	%
Age						
19–30	191	44.3	2335	35.1	3481	36.4
31–50	211	49.0	3413	51.3	4896	51.3
51–64	29	6.7	911	13.7	1175	12.3
Ethnicity						
White	183	42.5	3454	51.9	4916	51.5
Nonwhite	248	57.5	3205	48.1	4636	48.5
Sex						
Male	257	59.6	3451	48.7	5232	54.8
Female	174	40.4	3208	45.3	4320	45.2
IQ						
20–29	16	3.7	1102	16.5	1206	12.6
30–39	65	15.1	1657	24.9	1972	20.6
40–49	87	20.2	949	14.3	1250	13.1
50–59	107	24.8	1186	17.8	1605	16.8
60–69	136	31.6	1477	22.2	2085	21.8
70–74	20	4.6	288	4.3	395	4.1
Missing	0	0.0	0	0.0	1039	10.9
Vision						
No loss	328	76.1	4896	73.5	7108	74.4
Partial or total loss[c]	103	23.9	1763	26.5	2444	25.6
Hearing						
No loss	412	95.6	6071	91.2	8797	92.1
Partial or total loss[d]	19	4.4	588	8.8	755	7.9
Seizures						
None	351	81.4	5116	76.8	7591	79.5
Controlled and uncontrolled[e]	80	18.6	1543	23.2	1961	20.5
Residence						
Unsupervised	334	77.5	4683	70.3	7053	73.8
Supervised	97	22.5	1976	29.7	2499	26.2

[a] See text for exclusions.
[b] Excludes individuals aged <19 or aged >64 years, and individuals with measured IQ less than 20 or greater than 74.
[c] Includes 0 employed and 83 unemployed individuals with total vision loss.
[d] Includes 4 employed and 82 unemployed individuals with total hearing loss.
[e] Includes 7 employed and 190 unemployed individuals with uncontrolled seizures.

(Table 1). The apparent differences between IQ category percentages for the full and reduced datasets largely disappear after excluding individuals with missing IQ. Both the full and reduced datasets consisted of slightly more males than females and similar numbers of whites and nonwhites. Most individuals were aged 31–50, and lived in an unsupervised residence.

The employment rate of individuals who were unemployed in 1996 varied from 0–17.5% on a per-board basis. Mean and median employment rates per board were 6.1 and 5.0, respectively, with fifty percent of the employment rates falling between 3.0 (first quartile) and 9.3% (third quartile).

Coaches varied from 0.00 to 2.48 job coaches per 100 individuals, with mean and median values of 0.97 and 0.87 coaches per 100 individuals. Most individuals (82.6%) were served by boards employing between 0.5 and 1.5 job coaches per 100 individuals (Table 2). Most South Carolina counties were predominantly rural. However, larger populations in predominantly urban counties produced mean and median urbanization percentages of 51.0% and 52.5%. While a minority of counties reported unemployment rates below 6%, these counties represented nearly half (45.7%) of the study group. The three levels noted for the 75–100% urbanization category correspond to Charleston, Greenville and Richland counties, and to the cities of Charleston, Greenville and Columbia, respectively. Mean and median unemployment rates were 6.48% and 6.01%.

Table 2
Exposure and covariable information for study group

Exposure/covariable	Levels[a]	Unemployed in 1996[b]				Full 1997 file ($n = 9552$)[c]	
		Employed in 1997 ($n = 431$)		Unemployed in 1997 ($n = 6659$)			
		n	%	n	%	n	%
Job coaches per 100 individuals							
0–0.5	3	32	7.4	310	4.7	478	5.0
0.5–1.0	16	207	48.0	3879	58.3	5440	57.0
1.0–1.5	9	146	33.9	1623	24.4	2378	24.9
1.5–2.0	3	19	4.4	335	5.0	491	5.1
2.0–2.5	8	27	6.3	512	7.7	743	7.8
Missing[d]		0	0.0	0	0.0	22	0.2
Percent urbanization							
0–25	15	72	16.7	998	15.0	1436	15.0
25–50	17	106	24.6	1872	28.1	2562	26.8
50–75	11	128	29.7	2259	33.9	3223	33.7
75–100	3	125	29.0	1530	23.0	2309	24.2
Missing[d]		0	0.0	0	0.0	22	0.2
Per capita unemployment rate							
3-6	13	182	42.2	3058	45.9	4398	46.0
6-9	17	168	39.0	2305	34.6	3331	34.9
9-19	16	81	18.8	1296	19.5	1801	18.9
Missing[d]		0	0.0	0	0.0	22	0.2

[a]Corresponds to number of boards (coaches) or counties (percent urbanization, percent unemployment) within each exposure/covariable category.
[b]See text for exclusions.
[c]Excludes individuals aged <19 or aged >64 years, and individuals with measured IQ less than 20 or greater than 74.
[d]Unknown county.

The interaction between IQ and coaches was significant for the IQ 20–39 group ($\beta \pm 1$ SE $= 0.58 \pm 0.27$, $p = 0.03$) but not for the IQ 40–49 group ($p = 0.49$). For this reason, we merged the IQ 40–49 with the reference group (IQ 50–74). This action produced no substantial effect on the coach-IQ 20–39 interaction term ($\beta \pm 1$ SE $= 0.62 \pm 0.26$, $p = 0.02$).

The interaction between urbanization and coaches also varied with modifier level. Coach interaction was significant with the highest urbanization level (75–100%; $\beta \pm 1$ SE $= 3.04 \pm 0.57$, $p = 0.0001$) but was not significant with intermediate urbanization levels (25–50 and 50–75%, $p = 0.56$ and 0.43) and with a merged intermediate level (25–75%, $p = 0.31$). We then collapsed urbanization groups to 0–75% (reference) and 75–100%, with no substantial effect on the remaining, 75–100% coach-urbanization interaction term ($\beta \pm 1$ SE $= 3.02 \pm 0.52$, $p = 0.0001$).

The remaining 75–100% urbanization-coach interaction term was substantially influenced by the presence of Charleston county. Without Charleston county, for example, the estimated effect of the 75–100% term was reduced to nonsignificance ($\beta \pm 1$ SE $= 0.73 \pm 5.26$, $p = 0.89$). By contrast, dropping Greenville or Richland counties (while retaining Charleston county) produced little change in the interaction term estimate ($\beta \pm 1$ SE $= 3.20 \pm 0.64$ and 2.94 ± 0.58, respectively; $p \leqslant 0.0001$).

Interaction between county unemployment rate and coaches was significant for both the 3–6 and 6–9% terms. As the estimated parameters for these interaction terms appeared similar ($\beta \pm 1$ SE $= 1.02 \pm 0.27$ and 1.59 ± 0.31), we combined both levels. The resulting, single interaction term was also significant ($\beta \pm 1$ SE $= 1.21 \pm 0.25$, $p = 0.0001$). Coach interactions with age, health, race, residence, seizure status and sex were not significant [$p > 0.10$, except seizure status ($p = 0.068$)].

Potential confounders included age, health, race and sex. The relationships between coaches and potential confounders were significant for health and race ($p = 0.004$ and 0.0001) but not for age or sex ($p = 0.52$ and 0.13) (ANOVA). Based on models containing coaches and significant interaction and associated linear terms (i.e., employment, employment x coaches, IQ, IQ x coaches, urbanization and urbanization x coaches), race but not health significantly improved prediction of employment (Chi-square test, $p = 0.003$ and 0.10). Consequently, race was retained as a data-based confounder. Age and sex – despite nonsignificant relationships with coaches – were retained as population-based confounders. The final model in-

cluded the effect modifiers employment, IQ and urbanization, and the confounders age, race and sex.

The final model suggests significant, positive effects of job coaches on employment for individuals in highly urban counties, for individuals with IQ less than 40, and for individuals in counties with low or intermediate unemployment (Table 3). Regardless of IQ and unemployment rate, the effect of job coaches on individual employment was positive and significant in highly urban counties but nonsignificant or negative in rural or moderately urban counties. The exception was for individuals with IQ 20–39 in rural counties with low or intermediate unemployment. The "risk of employment" as a function of coaches was approximately two times greater for individuals with low than for high IQ, approximately three times greater for individuals in counties with low or intermediate unemployment and approximately ten times greater for individuals located in highly urban counties.

4. Discussion

The hypothesis that employment of individuals with MR would be positively influenced by the ratio of job coaches to individuals served was supported. However, this relationship was modified by county unemployment and by the IQ of the individuals served (Table 3). In rural and moderately urban counties, the effect of job coaches was significant and positive only for individuals with IQ 20–39 in counties with low to intermediate levels of unemployment.

The most important finding from these analyses is that job coaches continue to be successful in obtaining employment for individuals with IQ less than 40. This is noteworthy because it supports the original intent of the job coach program [7,12,20]. This finding suggests that early, positive findings in this field were not based on a buildup of individuals with extreme needs who might be atypical of individuals served recently.

The positive influence of low to intermediate unemployment may be explained by reduced competition for entry-level jobs when unemployment rates are low. Tight labor markets and the associated strong demand for employees may favorably influence the ability of individuals with MR to secure employment. By contrast, the effectiveness of job coaches may be limited in counties with high unemployment. In such cases, the county might reasonably offer non-competitive employment for individuals with MR.

Estimating the influence of urbanization on the effect of job coaches was complicated by the small number of urban counties in South Carolina and by high variability within these counties. The three counties with urbanization exceeding 75% (Charleston, Greenville and Richland) possessed similar sample sizes ($n = 514, 552$ and 589) but dissimilar employment rates (14.4, 4.3 and 4.6%) and job coach levels (1.08, 0.58 and 0.64 coaches per 100 individuals). Percent urbanization was highest for Charleston and Richland counties (88 and 85%) and lowest for Greenville County (77%). Finally, the job coach level for Richland County was derived for one board that serves both Richland County and an adjacent but less urbanized county (Lexington County, 59% urbanization).

The wide differences in employment rates and job coach levels in the 75–100% urbanized category yielded a relatively high variance for the associated interaction with job coaches. As a consequence, odds ratios for highly urbanized counties are presented with exceptionally wide confidence intervals (Table 3).

Any effect of urbanization may be explained by the presence of a wider variety of employment opportunities, of better trained job coaches and of reduced turnover of job coaches in highly urbanized areas. The relationship between job coach effect and urbanization in the present study may, however, be a product of one highly urbanized county only. Research from more urbanized states may provide better definition of the effect of urbanization on the job coach-employment relationship.

Previous research, including a prospective randomized trial using supported versus workshop employment, has shown that supported groups are more likely to obtain competitive employment [5]. Other predictors of competitive placement include job skills, behavior, job requirements, and wages and bonuses [8]. Others have shown that individuals with severe and profound MR can earn wages in community settings [18].

This evaluation process focused on identifying mutable factors that influence the likelihood of employment of individuals with MR. By identifying more of these factors, public health investigators will enable service providers to more effectively allocate employment-related resources.

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Table 3
Risk of employment as a function of job coach number[a]

Level of effect modifier			Relative risk (OR)	95% CI
Urbanization	IQ	Unemployment rate	of employment	
⩽75%	20–39	⩽0.09%	2.49	1.52–4.08
		>0.09%	0.72	0.42–1.23
	40–74	⩽0.09%	1.28	0.93–1.75
		>0.09%	0.37	0.24–0.55
>75%	20–39	⩽0.09%	25.70	10.21–64.66
		>0.09%	7.39	2.64–20.70
	40–74	⩽0.09%	13.18	5.87–29.61
		>0.09%	3.79	1.48–9.70

[a]Controlling for age, gender and race.

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VOCATIONAL SUPPORTS FOR INDIVIDUALS WITH ASPERGER SYNDROME

Meeting the Vocational Support Needs of Individuals with Asperger Syndrome
and
Other Autism Spectrum Disabilities

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Abstract

The purpose of this pilot study was to seek consumer perspectives on strategies for improving vocational placement and job retention services for individuals

with Asperger Syndrome and other autism spectrum disabilities (ASDs). For this purpose, 18 adults with ASDs were individually interviewed about their experiences within the workplace. Participants were asked to (a) describe positive and negative aspects of their vocational experiences, (b) identify major obstacles to successful employment, and (c) recommend appropriate vocational supports to be provided by vocational rehabilitation counselors, employers and co-workers. Qualitative analyses of the interview transcripts revealed a number of common experiences and concerns which suggest the needs of individuals with ASDs should be recognized as different from others with more generalized developmental disabilities and/or mental retardation.

Meeting the Vocational Support Needs of Individuals with Asperger Syndrome and

Other Autism Spectrum Disabilities

The purpose of this pilot study was to seek consumer perspectives on strategies for improving vocational placement and job retention services for individuals with Asperger Syndrome and other autism spectrum disabilities (ASDs). ASDs are characterized by significant social and perceptual deficits including (a) problems understanding social cues and facial expressions, (b) difficulty expressing emotions in conventionally recognizable ways, (c) inflexibility and discomfort with change, and (d) difficulty adapting to new tasks and routines. In spite of the fact that the majority of individuals with ASDs have no mental retardation, most report ongoing problems finding and maintaining jobs (Goode et al., 1994; Howlin, 2000; Lord & Venter, 1992; Nesbitt, 2000); and as a result of their difficulties understanding and responding appropriately to the social demands of the workplace, many continue to experience unemployment and underemployment (Nesbitt, 2000).

Although Asperger Syndrome and other ASDs are now estimated to affect between 1 in 500 (Bristol et al., 1996) and 1 in 100 individuals (Arvidsson et al., 1997; Wing, 1996), vocational support services for individuals with ASDs are virtually non-existent. Not only are state vocational rehabilitation programs rarely prepared to serve individuals with ASDs, but most individuals with ASDs – because they are not mentally retarded – are ineligible to participate in state and/or federally funded programs designed to assist individuals with other types of developmental disabilities. Although studies suggest that individuals with ASDs *can* experience success within the workplace given appropriate vocational supports (e.g., Howlin & Mawhood, 1996), the need remains for research identifying the types of supports that would most appropriately meet the unique challenges faced by individuals with ASDs. Extensive research suggests that vocational supports such as job development and on-site coaching (Kreutzer, Wehman, Morton & Stonnington, 1988), job-carving (Wehman, 1996), natural supports (Hagner, Butterworth & Keith, 1995), and other strategies have been helpful for individuals with other types of developmental disability. Little has been done, however, to determine whether or not the same or similar strategies would also benefit individuals with ASDs.

Based on the need for improved vocational support services for individuals with ASDs, as well as on recent recommendations that the voices and perspectives of individuals with disabilities be included as part of any intervention-oriented research design (Bersani, 1999; Meyer et al., 1998; Schwartz & Baer, 1991; Turnbull et al., 1998), this study addresses the question of appropriate vocational supports by interviewing 18 adults with ASDs about their experiences within the workplace. Participants were asked to (a) describe positive and negative aspects of their vocational experiences, (b) identify major obstacles to successful employment, and (c) recommend appropriate vocational supports to be provided by vocational rehabilitation counselors, employers and co-workers.

Methods

Participants

Criteria for participation in this study were as follows: (1) minimum 18 years of age, (2) self-reported difficulties with social cognition, (3) formal diagnosis of Asperger Syndrome or other autism spectrum disability *or* informal diagnosis of Asperger Syndrome based on DSM-IV criteria, (4) minimum one year in the workforce, and (5) no diagnosed mental retardation. Participants included 18 individuals who were selected to represent a wide range of ages, as well as diversity in terms of sex, education level, age when first diagnosed, and current employment status (See Fig. 1). Thirteen participants were formally diagnosed with Asperger Syndrome, two were informally diagnosed with Asperger Syndrome, two were formally diagnosed with high-functioning autism, and one was formally diagnosed with PDD-NOS. Participants were recruited via telephone calls and personal contacts. The research team sought nominations of potential participants by contacting families, teachers, therapists, and ASD and parent support groups throughout the San Francisco Bay Area. If nominees expressed a willingness to participate, researchers contacted them by phone to determine whether or not they met the general eligibility criteria and to answer any questions relating to the purpose of the study. All participants received a small honorarium for their time.

Instrumentation

Data for this study were based on 18 semi-structured individual interviews. The interview protocol comprised a series of open-ended questions designed to elicit information relating to participants' vocational experiences, barriers to success, and recommendations for improving job placement services as well as conditions within the workplace. After drafting a copy of the interview protocol, stakeholders (i.e., individuals with ASDs, parents, and professionals) were invited to provide input on the phrasing and sequencing of interview questions, and to comment on the social relevance of the study. Stakeholder recommendations were then incorporated into a final version of the interview protocol. Since several stakeholders suggested that participants would feel more at ease during their interviews if they knew what the questions were ahead of time, each participant was sent a copy of the interview protocol prior to his or her interview.

Data Collection

Interviews took place in locations of each participant's choice (e.g., participants' or researchers' homes, small conference rooms at local universities, etc.). Each interviewee participated in one semi-structured interview ranging from one to two hours . Before each interview, participants were told that they were free to end the interview at any time, and that they could refuse to answer any questions that made them feel uncomfortable. Interviews were audio-taped and later transcribed verbatim.

Analysis

Analysis of major and minor themes took place in two phases. The first phase of analysis involved the consensus-based development of a preliminary coding structure. Four of the most detailed interview transcripts were selected, and each member of the research team independently read the transcripts, identifying and labeling any statement pertaining to (a) positive or negative aspects of participants' vocational experiences, (b) major obstacles to successful employment, or (c) recommendations for appropriate vocational supports to be provided by vocational rehabilitation counselors, employers and co-workers (Strauss & Corbin, 1990). The team then met to compare and consolidate findings, and to develop a preliminary coding structure – i.e., a master list of major and minor themes (Strauss & Corbin, 1990). Any differences of opinion were resolved via consensus. During the second phase of analysis, QSR NUD*IST 4.0 – a software program for the organization and coding of qualitative data – was used to refine the coding structure and complete the coding process for the remaining interview transcripts. The first author took primary responsibility for this second phase of analysis, and the rest of the team provided feedback as well as confirmation of coding accuracy. Major themes were identified as themes mentioned by at least 50% of participants (i.e., 9 or more), and minor themes were identified as themes mentioned by at least 25% of participants (i.e., 5 or more).

Once major and minor themes had been identified, researchers looked for possible cross-group differences. In other words, researchers sought to determine whether or not differences in participant characteristics – including age, sex, education level, age when first diagnosed, and current employment status – could be correlated to the presence (or lack thereof) of certain themes within interviews. QSR NUD*IST 4.0 was used to isolate participant responses according to each of these participant characteristics (e.g., female/male, early diagnosis/late diagnosis, employed/unemployed, etc.), and to look for possible cross-group variations in response patterns.

Social Validation

This study was carried out in response to a need articulated during the First Annual Symposium on Asperger Syndrome at San Francisco State University. The research team made a number of efforts to ensure the social validity of the study. In addition to including the input of individuals with Asperger Syndrome and other ASDs during design of the interview protocol, an individual with Asperger Syndrome served as one of the main members of the research team. Furthermore, following completion of the data analysis phase, a "member check" was held enabling participants to provide feedback on the accuracy of

findings. Finally, based on recommendations from focus participants, plans are currently in place to incorporate findings from this study into a handbook for VR counselors, job coaches and employers on how to support individuals with ASDs in the workplace.

Results

Findings yielded a number of themes, 14 major and 35 minor, common across participants (See Figure 2 for summary of themes). These themes can be divided into three major categories, based on the three focal questions guiding this study: (1) overview of positive and negative experiences within the workplace, (2) major obstacles to successful employment, and (3) recommendations for appropriate vocational supports.

Overview of Workplace Experiences

Four major themes emerged in response to questions relating to positive and negative experiences within the workplace: (a) diverse vocational interests, (b) patterns of unemployment and underemployment, (c) work as a generally negative experience, and (d) exceptions to the rule – i.e., the isolated positive experience.

Diverse Vocational Interests All interview participants reported having held at least one job, and the majority reported having held multiple jobs. Participants repeatedly used terms such as "hard worker" and "good worker" to describe themselves; and expressed pride in their precision, attention to detail, and technical skill. Furthermore, in spite of stereotypes suggesting that autistic individuals are only interested in working in technical fields – participants reported choosing from a wide range of career paths, reflecting a diversity of vocational interests. Among other things, participants reported having worked as salespersons, art teachers, masseuses, library assistants, data entry clerks, photographers, forest managers, accountants, laboratory assistants, mapmakers, marketers, appliance repairpersons, food service workers, accountants, contractors, and military personnel, in addition to having worked as software engineers and computer programmers.

Unemployment and Underemployment Almost all participants, however, also reported lengthy periods of unemployment and/or underemployment, as well as lack of opportunities for career advancement. In the words of one participant, "I spent much more time being unemployed than being employed altogether." In the words of another, "The years roll by, and I stumble from one job situation to another, and nothing consummated into a promotion or career type move." Another referred to his job history as "sparse," and a fourth as having a "pretty checkered work career."

According to several participants, having to account for histories of unemployment and underemployment – as well as experiences of being fired repeatedly from jobs – often made it difficult to find new jobs. This is because job opportunities and career advancement are generally predicated on previous vocational success. Because of uneven job histories, several participants expressed frustration at being placed in entry-level positions for which they were

over-qualified. These participants had often prepared themselves for professional careers by completing graduate level coursework, yet found themselves working in food-services, or placed in low-level administrative or customer service positions doing simple, repetitive tasks.

Negative Work Experiences Almost all participants described the majority of their overall work experiences in negative terms. These negative experiences were frequently attributed to poor job matches, inadequate time to learn new tasks, lack of tolerance for difference within the workplace, and problems interacting with supervisors and co-workers – themes which will be discussed at greater length in the following sections of this article. Several participants reported that their repeated vocational "failures" resulted in financial hardship, feelings of depression and low self-esteem, and frustration at being unable to independently provide for themselves and/or their families.

Positive Work Experiences Although most participants were disappointed with their overall experiences of finding and maintaining jobs, however, most also reported isolated instances of vocational success. These successes were attributed either to participants having fortuitously found good job matches (e.g., positions which exploited participants' technical or mechanical skills but did not require a great deal of social competence), or to tolerant supervisors and co-workers who were willing to accommodate participants' differences. Several participants described supervisors who seemed to have a natural talent for building on their employees' strengths; and co-workers who were warm and open, in addition to being willing to assist participants in learning new tasks.

Obstacles to Successful Employment

Obstacles to successful employment were grouped into four major themes: (a) mastering the job application process, (b) acclimating to new job routines, (c) communication, and (d) navigating social interactions with supervisors and co-workers.

Job Application Process The majority of participants reported having difficulty with one or more aspects of the job application process. For instance, some participants reported difficulties creating resumes – in particular knowing which experiences and skills to highlight, and the degree of detail to provide. Individuals with ASDs often describe themselves as getting bogged down in the minutiae of a project, and finding it difficult to grasp the 'big picture' – characteristics which can make resume construction a daunting task. For similar reasons, several participants also reported difficulties filling out job applications. One participant described having difficulty figuring out "what [employers] wanted" from her, and another described realizing he had "answered [the employers'] questions in too much detail."

Several participants also reported difficulties with contacting potential employers by phone, as well as being interviewed for jobs. Individuals with ASDs often describe telephone conversation as a particularly taxing form of communication, and one participant described getting so nervous about making phone calls, that he would avoid making them if at all possible. This significantly reduced the number of jobs for which he could apply. Other

participants felt that their job opportunities were limited by the fact that they interviewed poorly – i.e., they reported feeling awkward or tense, and often did not know how to answer interview questions directly. This was somewhat analogous to the problem of putting together a resume, as participants were frequently unsure how much detail to provide. For instance, when asked to provide a brief summary of relevant work experiences, one young man launched into a lengthy monologue enumerating every job he had ever had. On the other hand, two participants felt that job interviews were relatively easy compared to the types of complex social interaction required on the job itself.

Finally, a number of participants described difficulties coordinating the job search process as a whole – i.e., knowing how to begin looking for a job, how to initiate job contacts, and how to follow-up on contacts once made. In the words of one participant, the main problem was "organizing, and starting, and knowing how to go about it." Again, participants related their difficulties to certain cognitive traits associated with ASDs – specifically difficulties prioritizing tasks and initiating activities.

Acclimating to New Job Routines A second major theme was that of habit formation. Individuals with ASDs have difficulty adapting to novel situations and routines, and often tend to shy away from new experiences because they find them both emotionally and cognitively taxing. Although individuals with ASDs are perfectly capable of learning new tasks, it often takes longer – and requires more intentional effort – than it would for a person without ASDs. Not surprisingly, almost all participants described problems adapting themselves to new job routines. Two participants described their difficulties in the following words:

> "I think probably one of the biggest problems I have is habituation or lack thereof. I just don't habituate at the same speed other people do."
>
> "After a while I finally learned [the job tasks] proficiently, but it took me a hell of a lot of time, and very specific effort."

Furthermore, the majority of participants worried that supervisors and co-workers – who were usually unaware of participants' diagnoses – would be critical of the fact that they needed additional time to learn new tasks. As two participants reported:

> "Sometimes it can feel kind of awkward when you're taking a little bit more time to do something, to go through something that other people have gone through faster. And you don't know how your supervisor is going to react to that. When I first started out, I wasn't that fast at all."
>
> "In a couple of my earlier jobs, my boss was very impatient with me for being fairly physically inept, and very slow to learn physical skills and manual skills."

Several participants reported that their inability to learn quickly ultimately led to

their being fired, and several others reported having been warned by their bosses that they would be let go if they didn't pick up the pace.

Communication A third major theme was communication. Individuals with ASDs frequently have difficulty processing incoming information, particularly when spoken rapidly. Furthermore, they often have difficulty "reading between the lines" and uncovering the implicit as well as explicit meanings of a message. As a result of these communication difficulties, the majority of participants described incidents wherein they had failed to understand instructions, and had therefore been unable to properly complete their work. Repeated miscommunications often led to poor work evaluations and/or being fired from the job. Ironically, when participants requested clarification from supervisors or co-workers, they were often reprimanded for asking too many questions, leaving participants in a sort of "catch-22" situation. For instance, one participant's supervisor refused to believe that his questions were genuine, and instead accused him of "challenging his authority."

Navigating Social Interactions The most frequently mentioned obstacle to vocational success – and the obstacle about which participants spoke most eloquently – was the inability to master the social demands of the workplace. ASDs are almost always characterized by difficulty navigating social situations. For instance, participants described having difficulty reading facial expressions and understanding tone of voice, knowing whether someone was teasing or being sarcastic, gauging the appropriate time to conclude a conversation, and understanding the purpose of casual workplace chit-chat. One participant described having a nagging feeling that a "whole social world was happening all around" him which he was unable to understand or take part in. Another participant tried to describe the perplexity he felt in the face of most workplace social situations:

> "I look at my friends who work at workplaces, and to me they're like social geniuses. I feel like somebody who's had a stroke and forgotten how to walk. You know, that's the closest metaphor I can get. You know, imagine if you're doing this thing that's completely natural to you. You have a stroke and you can't walk anymore. Or you can't speak. You have to learn all over how to do that again. That's sort of the closest analogy I can come up with for lacking any social skill."

This inability to make sense of social situations resulted in most participants' describing themselves as "odd," or "different from anybody at the workplace." As one participant put it, "More often than not, I've been regarded… as a round peg in a square hole or vice versa." While some participants were able to tolerate the experience of being socially "different," the majority of participants reported that their social deficits led to isolation and alienation in the workplace. One participant described feeling "a certain sort of stigmatization," and another described being "scorned" by co-workers.

Most participants expressed an awareness that vocational success frequently depended not only upon the ability to meet the technical requirements of the job, but upon one's ability to "fit in." As two participants reported:

> "I excelled at the work, but keeping the military image – the persona they wanted – I didn't do. Somehow I just didn't have an understanding of … the socialization part. I think I was missing something."
>
> "I don't know why I couldn't keep my jobs…. The real point of it is that I can't feel out a social situation well enough to figure out what [my co-workers] want in terms of personality, and then give them that, so I can keep my job."

Significantly, participants recognized that their social deficits often kept them from succeeding at their jobs – even when they were fulfilling their job descriptions in all other respects.

Recommendations for Vocational Supports

Recommendations for vocational supports were grouped into five major themes: (1) job matching, (2) individualized ASD-specific job supports, (3) communication supports, (4) autism awareness training, and (5) attitudinal supports.

Job Matching Almost all participants emphasized the importance of finding a job that was a "good match," and stressed the need for vocational rehabilitation counselors to learn how to develop jobs appropriate for individuals with ASDs. For many participants, job matching meant finding (or creating) jobs that took advantage of the skill/deficit profile associated with ASDs. Characteristics of a good job match were grouped into the following five minor themes: jobs which (a) built on technical skills – particularly savant skills or special interests/obsessions relating to ASDs, (b) required minimal social skill, (c) followed clearly defined routines, (d) allotted adequate time for learning new tasks, (e) did not result in excessive sensory stimulation, and (f) allowed for flexible work schedules.

Several participants recommended that individuals with ASDs be assisted to find jobs that take advantage of the mathematical, mechanical, visual/spatial, and object-oriented skills often associated with ASDs. For instance, reflecting on her vocational success as an accountant, one participant reported, "I've been somewhat fortunate in that the area that I chose to work in is dependent upon technical understanding." Another participant reported that working as an assistant art teacher had conveniently dovetailed with her strong visual and compositional sensibilities. Other participants pointed to the fact that many individuals with ASDs have particular savant skills or "obsessive" interests that could be put to good use in appropriate vocational contexts. In the words of one participant:

> "People on the ASD continuum – each one of us has a certain savant skill or collection of savant skills, and if we were allowed to, encouraged to indulge that vocationally to our heart's content… we could come up with some amazing solutions for various workplace

problems."

For other participants, a good job match meant finding a job that required minimal social interaction. For one participant, this meant starting his own business as a self-employed handyman, thereby "circumventing the social aspects of the job world – which has always been a major stumbling block." For other participants, this meant finding jobs that did not require regular interactions with customers or clients. Several participants stressed the importance of finding jobs wherein they could work semi-autonomously – i.e., without needing to check-in regularly with supervisors or interact continuously with co-workers. Significantly, one participant suggested that social interactions were not in and of themselves a problem so long as interactions remained "concrete" in nature. For her, working as an accountant meant that interactions were limited to discussions of materials and costs, and tended to follow a familiar script.

Participants also suggested that a good job match had to do with job structure. Several stressed the importance of finding jobs with clear and consistent daily routines. For instance, one participant described his job in the military as "comforting" because in his words, "I knew what my job was – what my duties were." For many participants, the ideal job was one that remained much the same from one day to the next, where tasks – once learned – were repeated again and again. As one participant described it, the ideal job does "not constantly [require] new unexpected things." For several participants, clear job structure also meant performing tasks one at a time and did not require 'multi-tasking.' In the words of one participant: "My task orientation or task performance tends to be sort of seriatim – it's sort of one thing at a time." Significantly, although participants frequently sought structure and sameness in their work, they also wanted to feel intellectually challenged by their jobs, and recognized that this was often a difficult combination to find.

Because of difficulties with habit formation, participants agreed that jobs that were good matches for individuals with ASDs would necessarily allow sufficient time for employees to learn new tasks. In the words of one participant, the ideal job "gives you a chance to learn [new] things, rather than being in a pressure situation where you have to learn instantly." Another participant who worked in the fast-food industry described the difficulty she had replacing an old routine with a new routine. She was particularly grateful for the fact that her boss was both patient and understanding, and took the time to accommodate her learning needs.

Although not all participants reported that this was a problem for them, another theme relating to job matching had to do with work environments that resulted in sensory over-stimulation. In the words of one participant, "I don't particularly like a lot of noise and crowds and business." Individuals with ASDs tend to be highly sensitive to visual, auditory, and tactile stimulation. Consequently, several participants reported they were more able to work productively if there was minimal ambient sound, natural or incandescent rather than fluorescent lighting, and a calm and tranquil workspace without a lot of distractions.

The final feature of a good job match was described as a flexible schedule.

Several participants reported that a full-time job placed too much pressure on them, and another participant described how his levels of productivity would often range dramatically from high one day to low the next. Several participants described themselves as slow but steady workers – and as one participant put it, longed "to find a work environment that could sort of fit that somehow."

ASD-Specific Supports A second major theme was the need for vocational rehabilitation (VR) counselors who were trained to provide individualized ASD-specific supports. The majority of participants expressed dissatisfaction with services they had received from the Department of Vocational Rehabilitation, and reported that the services they had received were neither adequately comprehensive nor tailored to meet the unique needs of individuals with ASDs. Recommendations for ASD-specific supports were grouped into the following four minor themes: (a) assistance with the job search process, (b) on-site job-coaching, (c) facilitation of social interactions, and (d) mentoring services.

Participants stressed the need for assistance with the job search process, and recommended that VR counselors not only direct individuals with ASDs to job listings, but assist them in contacting employers, following up with employers, and ensuring that work sites were appropriate matches for individuals with ASDs. Several participants suggested it would be useful if VR counselors were familiar with job sites, understood the actual requirements of specific jobs as well as the climate of the workplace, and had assessed the degree of tolerance and openness to diversity among supervisors and co-workers. One participant recommended that VR counselors have "in-depth knowledge of what the [job] is like…what the expectations are, all that. Instead of like, 'Okay, go out and find a job now.'" Another participant described the ideal role of the VR counselor as "building some bridges [individuals with ASDs] might not have been able to build themselves" – in other words, serving as the connecting link between individuals with ASDs and potential employers. Finally, participants stressed the importance of assisting with organizing the overall job search process. In the words of one participant, it would be good to have someone "take care of the many administrative details that were involved in searching for a job," including assistance putting together a resume and tailoring it to specific jobs, helping prepare for interviews, etc. One participant, for instance, suggested that VR counselors could help individuals with ASDs prepare for interviews by holding *faux* job interviews prior to the actual interview.

Participants also stressed the importance of continued support from VR counselors once individuals with ASDs had been hired – particularly in the first few weeks of a new job. Some participants described an actual "job coach," someone who was regularly on-site at least part of the time to help ensure a smooth transition. For instance, the job coach could provide extra job training assistance – reviewing the protocol for completing tasks, helping the individual with ASDs master each component of the job, etc. Others described someone who assumed a less conspicuous role, but was nonetheless available to field questions and trouble-shoot difficulties as they arose. For instance, several participants felt strongly that they would not have been fired from their jobs if someone had been available to advocate for them, and help clear up misunderstandings.

One domain where participants felt assistance would be particularly useful was in negotiating difficult social interactions. Several participants described a job coach-type figure who would be able to "translate" for the individual with ASDs. In other words, they felt they needed someone to help them understand how supervisors and co-workers think and communicate on one hand, and to help employers and co-workers understand how an individual with ASDs thinks and communicates on the other. As one participant described, "I didn't know there were problems until they blew up in my face." Another participant described thinking he had been fired, when he had only been suspended. A "translator" would facilitate communication between an employee with ASDs and his or her supervisor, helping to ensure that both parties are fully aware of where the other party stands.

Finally, several participants suggested that a mentorship program would be helpful – i.e., a program run by and for individuals with ASDs that would link less vocationally experienced individuals with more experienced mentors. Participants suggested that such a program would be useful because mentors could help novices prepare for and negotiate the types of challenges that arise in the workplace that are specific to ASDs.

Communication Supports Most participants stressed the importance of clear communication in the workplace. Because individuals with ASDs often have difficulty reading subtle communication cues, participants felt that it was particularly important that supervisors and co-workers be explicit in order to prevent miscommunication. One participant defined what clear communication meant to him:

> "Say *specifically* in words – no hidden meaning stuff, no in-between-the-lines stuff.... And give good details. You've got to have details specifically. We've got to have things broken down. And when we have things broken down, then we do great."

A number of participants reported frustration at the fact that supervisors – perhaps out of a desire to be polite – often expressed themselves indirectly and expected participants to second-guess their real meanings. Guessing the intentions of others is extremely difficult for individuals with ASDs, and the majority of participants stressed their preference for direct, even blunt, communication. One woman, for instance, appreciated getting regular bi-monthly evaluations because it helped her understand what parts of her work she was doing well, and what parts of her work could be improved. Without explicit feedback, she reported having no idea "where [she] stood."

Participants also recommended that supervisors avoid giving vague or partial instructions regarding the performance of tasks. As one participant explained, "[People with ASDs] are going to need: First you do 'a,' then you do 'b,' then you do 'c.'" Another participant suggested that – because prioritization does not come naturally for many individuals with ASDs – supervisors need to be explicit if certain tasks or components of tasks are more important than others:

> "As far as prioritizing – if it's more important to get this right than to get that right, *tell* them that. Because if you don't tell them that,

> they're going to be confused.... *Tell* them that. Out loud. Totally spell it out."

Finally, several participants stressed that supervisors and co-workers should not just explain how to do things, but should also *show* individuals with ASDs how to do things. The more visual and hands on, the better. Furthermore, a number of participants recommended the use of written instructions as a supplement to oral instructions. In the words of one participant:

> "I think writing out the instructions of what [the supervisor] wants done. That's a biggie. If [he] writes it out – 'this is what has to be done' – you're not wondering if there are any loose ends, which was a constant problem for me."

Significantly, according to several participants, a supervisor's willingness to use multiple modes of communication – i.e., speech, writing, and modeling of behavior – often helped get the message across more clearly than simply using one mode or another.

Autism Awareness Training Another major recommendation was autism awareness training. Most participants reported disappointment with existing levels of knowledge about ASDs among members of the public – and particularly among VR counselors. As one participant put it:

> "I think that this would be of paramount importance for [VR counselors] to have that training.... There's nothing that could substitute for that. And they should get the training before they have occasion to run into somebody like that. They may not be prepared for it if they haven't had any prior training at all."

Participants felt that autism awareness was key not only for VR counselors, but also for employers and co-workers. According to several participants, communication breakdowns and firings could often be averted if supervisors had a better understanding of ASDs. For instance, one participant explained that it would be useful for his supervisor to know more about ASDs, because then – instead of being perceived as rude or aggressive – his supervisor would realize that he was merely being unintentionally blunt.

In terms of educating the public, several participants reported having taken the matter into their own hands. One participant disclosed the fact that he had Asperger Syndrome to all of his co-workers, and distributed an article on Asperger Syndrome to help them better understand who he was and why he behaved the way he did. Another individual described educating his job coach about ASDs, because his job coach had never met anyone with Asperger Syndrome, and was therefore unaware of the types of vocational challenges unique to this population.

Attitudinal Supports Finally, the majority of participants stressed the importance of attitudinal supports for vocational success. Several participants – in describing their vocational successes – described work environments where co-workers were open-minded and tolerant of differences. Many described

relationships with supervisors and co-workers who were "patient," "caring," and "supportive," and one participant described a positive relationship with a co-worker in the following terms: "This one woman, she has kind of taken me under her wing in a most unassuming fashion." Although attitudinal supports were not in and of themselves enough to guarantee vocational success, the attitudes of supervisors and co-workers clearly had a powerful effect on participants' perceptions of themselves as part of the workplace team.

Cross-Group Differences

No significant thematic differences appeared to be correlated to participants' sex, educational level, or employment status. However, certain cross-group differences did appear to be related to age and/or age of diagnosis. These characteristics were themselves correlated, since younger participants were more likely to have received accurate and timely diagnoses. Older participants, on the other hand, often went undiagnosed until much later in life (See Fig. 1 for ages and ages of diagnosis).

Younger participants (under the age of 30), and individuals who were diagnosed with ASDs while still in school, tended to have fewer negative work experiences. They were also more likely to have received the benefits of special education services, and therefore to have felt entitled to vocational support services following graduation. Because of the higher level of autism awareness among this younger group of participants, these participants tended to have had more positive overall work experiences (often having been placed by transition teachers who were particularly sensitive to their needs), and to have a more positive outlook relating to their career options. Furthermore, younger participants were more likely to have reported receiving adequate supports from VR counselors and job coaches. These cross-group findings suggest that although job supports for individuals with ASDs are still far from adequate, things are improving. Younger participants are not only confident of their abilities, but also aware of their diagnoses, conscious of the types of obstacles they face in finding and keeping jobs, and willing to seek out and demand the vocational support services to which they feel entitled. Furthermore, these findings suggest that VR counselors and job coaches may be more aware than they used to be of ASDs and the unique vocational challenges faced by individuals with ASDs.

Limitations

Results of this study should be interpreted with the following limitations in mind. First, participants were all recruited from a single geographical region – the San Francisco Bay area. It is possible that findings may not generalize to areas with significantly different demographic characteristics – for instance rural and suburban communities as opposed to major metropolitan areas, etc. Furthermore, participants were all of European descent, and were therefore relatively ethnically homogeneous. It is possible that if individuals from other ethnic backgrounds had been recruited, they would have reported additional challenges such as stigmatization or discrimination based on race.

Discussion

Results of this pilot study suggest that individuals with ASDs require somewhat different vocational supports than those currently being recommended for individuals with other types of developmental disability and/or more generalized mental retardation. Although many of the vocational supports recommended by participants were similar to strategies considered best practices for individuals with other types of developmental disability – specifically the individualized services of a job-coach – participants in this study emphasized vocational supports that would address their unique difficulties with social cognition and habit formation. Furthermore, they stressed the importance of job matches that not only accommodated ASD-related weaknesses/deficit areas, but also exploited individuals' ASD-related strengths.

Based on focus participants' suggestions, it is recommended that the job coach be someone who will not only help individuals with ASDs navigate each step of the job application process, but will also be available on an as-needed basis to assist individuals with ASDs in understanding and handling the nuances of routine workplace social interactions; monitor work-related communications; and explain to bosses and co-workers the importance of expressing themselves clearly and directly. A job coach serving individuals with ASDs should be able to provide social skills training tailored to meet the needs of particular individuals as well as specific work sites. The job coach should know how to analyze the unique "culture" of each workplace and identify the types of social competencies that would be most helpful for individuals with ASDs to acquire – e.g., knowing whether it is necessary to ask work-related questions during formal meetings with the boss or if it is okay to ask questions as they arise; knowing how to interpret indirect feedback on job performance; and being able to engage in "water cooler chit-chat" with co-workers. Furthermore, the job coach must be able to provide explicit instruction in these areas – spelling out the way in which bosses' and co-workers' body language, tone of voice, and facial expression communicate subtle, albeit important, messages. If job coaches are unable to provide this type of explicit social skills training, they should make appropriate referrals to local ASD professionals.

Focus participants also mentioned habit formation as a particular challenge for individuals with ASDs in the workplace. Unlike individuals with mental retardation, individuals with ASDs are frequently capable of performing extremely complex work-related tasks. Like individuals with mental retardation, however, individuals with ASDs often require intensive one-on-one instruction, as well as lengthy practice sessions, before they are able to complete work-related tasks independently and efficiently. Consequently, we recommend that job coaches be skilled in task analysis – i.e., know how to break larger tasks into smaller, more manageable parts. Written instructions can also be useful in helping individuals with ASDs memorize the order in which to complete parts of tasks. It is expected that job coaching services for individuals with ASDs would initially involve more energy and resources "up front," but once tasks have been mastered, would be considerably less intensive.

Findings also suggested that vocational support services for individuals with ASDs should not just make-up for social and cognitive deficits, but should also take advantage of the skills or "benefits" associated with ASDs. Most participants – while painfully aware of the challenges associated with ASDs –

also reported feeling a certain pride in their ASDs. They felt, however, that Vocational Rehabilitation and other job placement services rarely tapped into the strengths of ASDs, and tended instead to treat ASDs as merely one of many possible disabilities. Job matching should not merely involve the identification of jobs with minimal client contact, but should also identify jobs which exploit individuals' areas of strength – e.g., software design or editorial tasks which require painstaking attention to detail. Passionate interests should also be explored – i.e., job placement services should seek to identify individuals' interests in animals, numbers, transportation services, photography, books, computers, etc.

Significantly, participants' isolated experiences of success in the workplace suggest that with minimal resources and supports, positive vocational outcomes are indeed possible. The importance of a good job match cannot be underestimated. For instance, one participant described satisfaction with her current job as a corporate accountant, explaining that the job was a good match for her because (a) it took advantage of her obsessive attention to detail, and (b) social interactions were infrequent, and when necessary followed a predictable script. Another participant attributed a particularly successful job experience doing data entry to the fact that (a) his boss took the time to sit down and clarify her expectations using clear and explicit language, as well as to provide regular feedback on his performance; and (b) his co-workers were tolerant of his social shortcomings, and willing to assist him when necessary in getting the job done.

These isolated success stories suggest that if more intensive configurations of support could be offered at times of new job placements and critical transitions, individuals with ASD are likely to exhibit remarkable degrees of independence and competence. Although individuals with ASDs are capable of vocational success, however, the odds are stacked against them as long as appropriate vocational supports are in short supply. All participants reiterated the need for the Department of Vocational Rehabilitation to provide ASD-specific supports, and to contract with external agencies if necessary. Only via improved services did participants feel they would have better success at finding and retaining jobs.

This study has drawn on the perspectives of adults with ASDs in an effort to better understand the strategies necessary for improving workplace outcomes. Whenever possible, we have sought to describe experiences, obstacles, and recommendations for improved vocational services in participants' own words. Members of the research team were repeatedly impressed by the extreme thoughtfulness of participants, their abilities to clearly articulate both negative and positive aspects of living and working with ASDs, and the level of creativity that went into their recommendations for improved vocational supports. The results of this study strongly suggest that individuals with ASDs should be included in future research efforts to define appropriate vocational interventions. Future research efforts would also benefit from including the voices of employers, VR counselors, and job coaches.

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CRP-RCEP Region III

Fact Sheet December 2007

Supporting Individuals with Autism in Community Jobs: Identifying Strategies to Facilitate Success

Introduction

People with autism are significantly underserved in terms of achieving employment outcomes supported by the state/federal vocational rehabilitation (VR) program. While the data available is based on a narrow definition of autism used by the Rehabilitation Services Administration (RSA), only 0.6% of all successful VR closures in 2005 were individuals with autism. The actual number of successful closures in 2005 for individuals with autism was 1,141 (Dew & Alan, 2007). A VR closure is considered successful when:

- The VR services provided under an Individualized Plan for Employment (IPE) substantially impacted the customer's job at the time of closure.
- The individual obtained his or her vocational goal.
- The individual maintained employment for a minimum of 90 days.

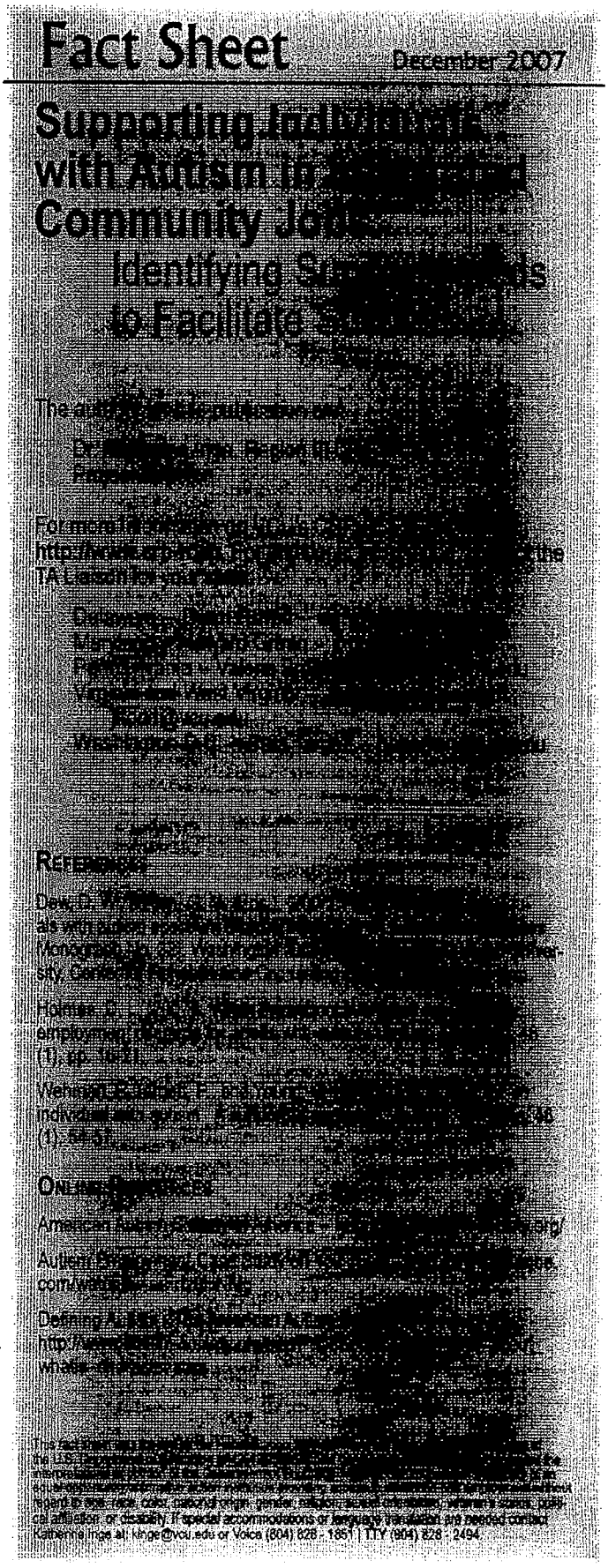
Perhaps as critical are the number of unsuccessful closures for individuals with autism and the proportion of unsuccessful closures to successful closures. In 2005, there were 1,689 unsuccessful closures with a proportion of unsuccessful to successful closures of 1.48 (1689:1141) (Dew & Alan, 2007). This data published by RSA clearly illustrates the poor employment outcomes of individuals with autism spectrum disorders in this country.

These employment outcomes are even more alarming when considering the information from a 2007 report from the Centers for Disease Control (CDC). The study found that 1 in 150 children in America today have an autism spectrum disorder (ASD) (CDC, 2007). The Autism Society of America (ASA) estimates that 1.5 million Americans and their families are now affected, costing the U.S. at least $35 billion annually. In light of this information, employment is critical if individuals with autism spectrum disorders (ASD) are to become participating members of society.

Integrated competitive employment should be a goal for all individuals with autism who wish to work and should be the first choice offered .The current unemployment statistic may be related more to services and supports that individuals with autism do not receive. Holmes (2007) indicated that a major reason for underemployment, unemployment, and job loss of individuals with autism is a failure to determine the supports needed as well as the most effective way to design the supports. Individuals with autism can be successfully employed when the proper supports are identified, put into place, and evaluated periodically to ensure effectiveness. This fact sheet will provide information of strategies and supports that Community Rehabilitation Providers (CRPs) can provide to assist individuals with autism in achieving integrated employment outcomes.

Individualized Support Needs and Autism

Any individual has unique characteristics that will impact the type of job, which the person will need to be successfully employed. For instance, one person may do well in a job that requires a great deal of public contact while another performs best when the work setting has limited interactions with customers. This is true of individuals without disabilities as well as those who have disabilities regardless of the type or severity of the disability.



There are some unique behavioral characteristics that are associated with autism. CRPs who want to assist individuals with autism find and maintain a job in the community, may find it useful to understand some of these unique characteristics. Remember, there will be a great deal of variability across skills, interests, and behavioral characteristics of individuals with autism. This section is presented with a caution that the employment specialist should not assume that all individuals with autism have the same support needs just because the person has autism. Getting to know each individual and his or her interests and abilities will be key to a successful employment outcome.

Key Points

- There is no specific strategy that will work for all individuals with autism in all employment settings.
- The person with autism is an individual with unique skills and abilities as well as support needs. All people with autism are not alike.
- The employment specialist must analyze not only the characteristics of the employee, but also the characteristics of the work site and its employees.
- Information obtained in natural environments about the individual (e.g. home, restaurants, the mall, school, etc.) is generally more useful to the employment specialist versus information from segregated environments (e.g. sheltered workshop, special education classroom, etc.).
- Some characteristics displayed by individuals with autism may be beneficial in specific work settings rather than negative if the individual is matched to the right job.

Characteristics

Difficulty communicating: Recognize that individuals with autism have a wide range of communication skills. Some may repeat words or phrases instead of engaging in conversation. Others may be nonverbal and yet have intellectual abilities. Assume competence rather than assuming that the individual's lack of communication is associated with cognitive limitations. For support needs related to communication, determine if an accommodation may minimize the disability.

Strategy: John has difficulty communicating and sometimes is not responsive when someone speaks to him. His supervisor communicates with him about his work tasks using e-mail. John does well with this strategy and also is able to ask his supervisor's and coworkers' questions using this strategy.

Limited social skills: Social interactions on the job have been identified as critical to job success and retention. Social skill requirements on the job can present difficulty for individuals with autism. An employment specialist will want to understand the social characteristics of the individual seeking employment as well as the social demands of any potential workplace. Some of the characteristics that may be observed are the individual's preference to being alone, aloof manner (e.g., does not smile or greet coworkers, has a fixed stare in social situations), little or no eye contact, or laughing (and/or crying) for no apparent reason. Individuals with autism also may have difficulty initiating or sustaining conversation with others even though the person has speech.

Strategy: Be sure to observe the individual's social skills and consider how matching the person to a work environment can accommodate limitations. As an example, Mary appears to be unaware of the importance of using "social graces" in communicating with others. She can appear to be blunt or unfriendly such as not smiling or greeting coworkers when arriving at work. Matching Mary to a job where social skills are not needed, or one where the coworkers are supportive of one another would be important. With Mary's permission, the employment specialist could discuss with her coworkers that while she may seem aloof and unfriendly, this is a characteristic of her disability. A supportive work environment over time also may help Mary improve her social skills.

Unusual behaviors: Individuals with autism may have usual behaviors that have presented a barrier to ingrated employment. For instance, an individual may insist on "sameness" in his or her work environment such as wanting all work supplies or personal belongings to be placed in a specific arrangement and becoming upset if there is a change. Another example of wanting "sameness" in the workplace might be resistance to change in routines. A person with autism might not respond or become visibly upset if a coworker or supervisor asks him or her to stop work on a regularly scheduled task to complete something new. Another unusual behavior that has typically been associated with autism is the individual engaging in repetitive movements. The person spinning objects or waving a hand in front of his or her face might characterize this behavior. Remember that each person is unique, and an individual may or may not display unusual behaviors just because he or she has autism.

Strategy: CRPs are advised not to limit a person's access to employment opportunities because of unusual behaviors. A good job match can minimize atypical behaviors or perhaps may even be considered strength in some work environments. For instance, the individual who requires consistency in his or her daily tasks can make an excellent employee! However, if this same person is placed in a job where there is no consistency in daily routines, it is unlikely that individual will be successful. Also consider, that as the person becomes comfortable with the workplace, behaviors may not be an issue or may decrease. For instance, the individual who makes loud noises when feeling insecure of uncertain of what is expected may over time only occasionally make loud noises. Again, a match between the person and the environment is important where simple accommodations can be made to support the individual. Example: John has a behavior in which he will clap his hands over his ears every few minutes and hum loudly. If he is able to wear headphones while working, this behavior does not interfere with his work performance.

Key Points

- Be sure to consider features of a work place, which either meet the needs of the individual's characteristics or can be adapted to support the person.
- Identify worksites that will offer minimal exposure to issues or things that have been known to contribute to behavior challenges.
- Negotiate accommodations that will address specific individual characteristics that cause barriers to employment.
- A job analysis of potential jobs should look at all issues related to environmental factors (e.g., noise, light, temperature); coworker supports (e.g., amount of available supervision, social demands of the workplace); and types of job tasks (e.g., down time, production requirements, number of job duties, routine, and job complexity.)
- Always involve the supervisor, coworkers, and the individual in the identification and the design of any workplace accommodations.

Improved Employment Opportunities For People with Disabilities

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7. MEANING AND VALIDITY OF THE UNABLE-TO-WORK MEASURES

As discussed in Section 5, a person's self-assessment of his or her ability to work may be influenced by many considerations besides health and impairment, including environmental factors such as negative employer attitudes and workplace barriers. Nevertheless, as we will see in this section, self-reported inability to work is closely associated with various measures of both poor health and severe functional limitation. We begin by exploring the principal health conditions and impairments identified as causing activity limitation among those reporting inability to work.

What conditions are associated with inability to work?

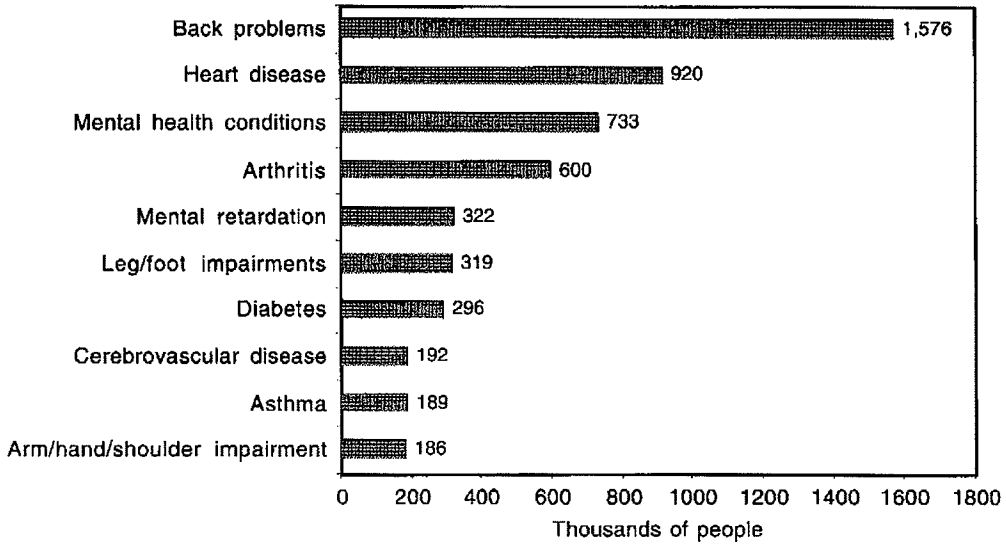
According to data from the NHIS core on health conditions and impairments causing activity limitation, back problems[4] are by far the most prevalent main cause of inability to work, affecting 1.6 million working-age adults (Figure 19). Heart disease[5] is the second-leading cause, affecting 920,000 people. Since these are also the top two causes of disability overall (LaPlante & Carlson 1996), it is no surprise that they are so highly ranked as causes of inability to work. More unexpected is the third-rank presence of mental health conditions[6], which is the main reason listed by 733,000 working-age adults for their inability to work. Arthritis[7] is fourth, affecting 600,000 people.

Other highly prevalent conditions include mental retardation, impairments of the leg or foot, and diabetes[8], each of which is the main cause of inability to work for about 300,000 working-age adults. Cerebrovascular disease, asthma, and impairments of the arm, hand, or shoulder[9] each affect just under 200,000 people as the main reason they cannot work.

Rapid growth in some causes of inability to work

Trends in prevalence of the four top-ranked conditions, as primary causes of inability to work, are shown in Figure 20. Both back problems and

Figure 19. Most prevalent conditions causing inability to work among working-age adults, 1988–1996.



[4] Defined as three-digit ICD codes 720 through 724 or NHIS impairment code X80.
[5] Three-digit ICD codes 390 through 429.
[6] Three-digit ICD codes 290 through 316.
[7] Three-digit ICD codes 714, 715, or 716.
[8] NHIS impairment code X19, impairment code X86, and three-digit ICD code 250, respectively.
[9] Three-digit ICD codes 430–437, three-digit ICD code 493, and NHIS impairment code X84, respectively.

NHIS impairment codes, with low-prevalence conditions omitted. For each condition, three quantities are calculated for the population whose disability is primarily caused by that condition:

- the proportion unable to work;
- the *poor health index*, defined as the mean of the poor health scale—2 for poor health, 1 for fair, and 0 for good or better;
- the *functional limitation index*, defined as the mean of the functional limitation scale—3 for a severe limitation as defined above, 2 for a moderate limitation as defined above, and 0 for a slight limitation or none (because slight functional limitations are not captured in the survey for most functional dimensions, we have omitted them from the scale).

Figure 27 shows the poor health index vs. the proportion unable to work for each of the 128 health conditions and impairments that cause disability with sufficient prevalence. With a correlation coefficient of 0.67, the association between poor health and inability to work is clear, and there is a definite tendency for conditions resulting in worse health to also cause higher levels of inability to work.

Conditions causing the worst health also cause the vast majority of the people who have them to consider themselves unable to work. These conditions, which appear in the upper right-hand corner of the graph, include heart failure, lung cancer, hypertension, and emphysema. The highest prevalence conditions, however, representing the bulk of the disability population, appear in the lower two-thirds of the graph, close to the diagonal.

Also of particular interest are those conditions appearing far below and to the right of the diagonal, including schizophrenia, quadriplegia, blindness, paraplegia, and mental retardation. Most of the people with these conditions (in total a very small fraction of the disability population) are in

Figure 27. Proportion unable to work vs. Poor Health Index, by main condition causing disability.